

# For people with intellectual and developmental disabilities

# 2014 Chapter Activity Report

In 2014, The Arc of Colorado continued to focus on critical issues identified by the Board of Directors in 2013:

- Public Policy Advocacy
- Public Awareness
- Outreach to areas of Colorado not served by local chapters of The Arc
- Governance
- Financial Resources

# **Public Policy**

#### **Federal**

The Arc of Colorado regularly informed members of the Arc and other organizations who advocate with and for people with intellectual/developmental disabilities about federal issues affecting the supports and services that provide "lifelines" for people with disabilities. While the second session of the 113<sup>th</sup> Congress was less active than we would have preferred, The Arc persisted with advocating for important federal initiatives including:

- Social Security disability programs
- Supplemental Security Income
- The Affordable Care Act
- Full funding for IDEA
- The ABLE (Achieving a Better Life Experience) Act to allow people with disabilities to open tax-advantaged savings accounts
- Improvements to Home and Community Based Services for people with IDD through expansion of self-direction options and person centered system design
- Medicaid buy-in expansion
- Overcoming barriers to economic self-sufficiency for people with disabilities
- Closure of segregated, sub-minimum wage workshops for people with IDD
- Passage of the Convention on the Rights of Persons with Disabilities
- Support for Declaration of The Rights of People with Cognitive Disabilities to Technology and Information Access

Representatives from The Arc of Colorado and other CO local chapters of The Arc attended the annual Disability Policy Seminar sponsored by The Arc and UCP (United Cerebral Palsy), AAIDD (American Association on Intellectual and Developmental Disabilities), AUCD (Association of University Centers on Disabilities), SABE (Self Advocates Becoming Empowered), and NACDD (National Association of Councils on Developmental Disabilities). We met with Senators Bennet and Udall, Representatives Coffman, Polis, Tipton, and Gardner, and with staff from the offices of Representatives DeGette, Lamborn, and Perlmutter.

Each year, The Arc, UCP, AAIDD, NACDD, AUCD, and ANCOR (American Network of Community Options and Resources, collaborate in developing a Congressional public policy agenda. The Arc of CO, along with 700 other state and local chapters of The Arc work at state and US House district levels to promote issues related to Medicaid, Health Care, Long Term Community Services and Supports, Social Security/Income maintenance, Employment, Education, Direct Support Professionals, Family Support, Criminal Justice, Housing, Civil Rights, and Technology.

The Arc of Colorado Executive Director participates in bi-monthly calls on federal legislation with The Arc Policy office, and shares updates on critical issues with local chapter executives and others interested in The Arc policy agenda.

The Arc of Colorado Executive Director with the Associate Executive Director of The Arc of Indiana represented The Arc at the National Conference of State Legislatures annual conference in Minneapolis, MN in August, 2014.

# **Public Policy**

#### Colorado

The 2014 General Assembly avoided many of the controversial issues that dominated the previous year's legislative session, not surprising for an election year. Both chambers of the Legislature were supportive of the Governor's budget which provided for significant increases in support for people on the Wait List. The Arc of Colorado, with local chapters and the support of our lobbyist, Mendez Consulting, actively participated in advocating for (and occasionally against) legislation that impact people with IDD.

In March, 2014, The Arc of Colorado hosted a luncheon for CO legislatures and staff and Board members of local chapters. The 2014 luncheon was well attended and allowed local chapter members time to visit with Senate and House members from their communities.

#### 2014 General Assembly action

- Budget—long bill:
  - Funding for 2,040 new resources for people on the wait list for the Supported Living Services (SLS) HCBS waiver
  - 25% increase in spending authorization limits for the SLS waiver
  - Increase in maximum annual limit for SLS recipients from 35,000 to \$43,750 for the SLS waiver
  - Other new resources: DD Comp waiver and SLS waiver: 28 for youth aging out of the child welfare system, 40 for adults who experience emergency or crisis situations, 30 for people transitioning from the Regional Centers or Mental Health Institutes, and 61 for youth transitioning from Children's Extensive Services waiver (CES)
  - $\circ~$  A rate increase of 2% for all providers
  - A total increase in funding for Family Services and Supports Program (general fund only) of \$3.4 million

Other bills passed by the General Assembly, signed by the Governor and enacted into law:

- **HB 1017:** Rep. Duran and Sen. Ulibarri—<u>expands availability of affordable</u> <u>housing.</u>
- HB 1029 Rep. Primavera and Sen. Todd—makes changes to statute related to parking placards for persons with disabilities.
- **HB 1032:** Rep. Kagan and Sen. Guzman-makes provisions for <u>juveniles charged</u> with crimes to have access to legal counsel.
- HB 1051: Reps. Schafer and Landgraf and Sens. Kefalas and Crowder: requires state departments to develop a strategic plan to address the wait list for IDD <u>Services</u>.
- **HB 1162:** Rep. Landgraf—in cases of rape wherein a child is conceived, <u>adds</u> <u>additional protections re: parental rights of victim.</u>
- **HB 1211:** Rep. Young and Sen. Tochtrop—<u>makes CO services conform with</u> <u>federal law re: Medicaid accessibility for complex medical rehabilitation.</u>

- HB 1252: Reps. May and Gerou and Sen. Hodge—allows transfer of funds from the DD Cash fund to <u>support expenses of capacity building in the IDD service</u> <u>system.</u>
- **HB 1301**: Rep. Mitsch-Bush and Sen. Kerr-changes in state law regarding <u>safe</u> routes to schools for all students.
- **HB 1303**: Reps. Scott and Ferrandino and Sen. Schwartz—bill to allow testimony to the Legislature from remote locations.
- **HB 1317**: Rep. Duran and Sens. Nicholson and Kefalas—<u>changes payments and</u> <u>subsidies for child care for parents receiving public benefits</u>; creates a sliding scale of payments based on income and makes allowances for payment to providers when children are absent.
- **HB 1338**: Rep. May and Sen. Hodge—<u>Creates Regional Center Legislative Task</u> <u>Force</u> to make recommendations about the utilization of state and Medicaid resources at the RCs and requires a facility utilization review:
- HB 1360: Rep. Young and Sen. Aguilar—Home Care Licensure sunset—allows for <u>Home Care Licensure requirements to move forward for five years;</u> requires review of HC requirements vis á vis SLS and CES requirements; exempts PASA's from surveying under HC licensure rules; creates funding for licensure requirements for small agencies.
- HB 1368: Rep. May and Sen. Hodge—requires that <u>youth with IDD in the child</u> welfare/foster system be transitioned to adult DD services at the age of 18. Allows for exceptions to be made in extraordinary circumstances.
- **SB 005**: Sen. Ullibarri and Rep. Singer—adds assurances to CO labor law <u>to</u> <u>protect right of minimum wage earners.</u>
- **SB 012**: Sen. Kefalas and Rep. Exum—changes formula for the CO <u>program for</u> <u>the Aging and Disabled</u> to tie <u>increases in funding to a %age of income related</u> <u>to federal poverty levels.</u>
- **SB 050**: Sen. Aguilar and Rep. Moreno—<u>requires hospitals to provide financial</u> <u>assistance information to all patients</u> and <u>limits</u> the amount that is charged for private pay to a %age of Medicare reimbursable rates.
- **SB 059**: Sen. Guzman and Rep. Lawrence—<u>allows for felony crimes committed</u> <u>during the course of a rape to be prosecuted</u> if DNA identifies probable cause for an indictment even if the statute of limitations has run out on the felony crimes.
- **SB 098:** Sen. Zenzinger and Rep. Schafer—establish additional penalties and <u>strengthens reporting requirements for crimes against elders</u>
- **SB 118:** Sen. Steadman and Rep. Melton—<u>add additional protections for persons</u> <u>with disabilities</u> by strengthening CO laws to conform with new changes to the ADA.
- SB 130: Sen. Tochtrop and Rep. Primavera—<u>increases personal care allowance</u> for people living in Medicaid funded nursing facilities from \$50 to \$75 a month
- SB 187: Sens. Aguilar and Roberts and Reps. Stephen and Schafer-create the <u>CO Commission on Affordable Healthcare.</u>

#### Other State Public Policy Activity

• Community Living Advisory Group. The CLAG submitted recommendations to the Governor in September of 2014 for major changes in Colorado's system of long term services and supports. The Executive Directors of The Arc of Colorado and The Arc of Arapahoe and

Douglas served on the CLAG. The ED of The Arc of Colorado co-chaired the sub-committee on Waiver Simplification. CO Chapters of The Arc served on several sub-committees.

Recommendations addressed:

- Waiver simplification
- Care coordination
- Single entry point re-design
- Regulatory reform
- Workforce development
- Employment
- Quality assurance

The Governor's 2015 budget requests funding to extend the CLAG through 2016.

- Adults with IDD HCBS Waiver Re-Design—this task force is charged with making recommendations for a single HCBS waiver for adults with IDD to be submitted to CMS, after a public review process, in late 2015 for implementation in 2016. The new waiver would provide for a seamless and flexible array of services and supports that could change as the needs and aspirations of those receiving services change. Options for a range of self-direction and individual budget control would be included. The Executive Directors of The Arc of Colorado and The Arc of Arapahoe and Douglas serve on the task force.
- Colorado Cross Systems Crisis Intervention and Prevention—Gap Analysis—The Medical Mental Health sub-committee of CANDO (Colorado Collaborative for Autism and Neurodevelopmental Disabilities Options), through a contract between JFK Partners and the CO Division for Intellectual and Developmental Disabilities (DIDD), completed an analysis of the gaps in Colorado's publicly funded systems for mental health services for people with neurodevelopmental disabilities and co-occurring needs for mental health treatment and behavioral supports. The report was submitted to DIDD in September of 2014 and will be released this fall to the Joint Budget Committee and the General Assembly. The report identifies barriers in the current system and makes recommendations for policy and funding changes.

Dr. Corry Robinson, Carol Meredith and Marijo Rymer were invited to present information on the project and the recommendations to:

- Alliance Leadership Summit
- Colorado DD Council
- The Arc National Convention
- Coleman Institute annual conference

The Medical Mental Health committee of CANDO (co-chaired by the Executive Directors of The Arc of Colorado and The Arc of Arapahoe and Douglas) will continue efforts to implement the recommendations identified in the report. Regular meetings with Alliance and the Colorado Behavioral Healthcare Council will continue in 2015.

- HB 1338—Regional Center Task Force—The Executive Director of The Arc of Colorado was appointed to a task force charged with making recommendations to the General Assembly regarding the utilization of the current state operated institutions in Pueblo, Grand Junction, and Wheatridge.
- Colorado Community Choice Transition— The Executive Director of The Arc of Colorado was appointed to serve on the CCT Advisory Council to advise CHCPF on implementation of the Money Follows the Person grant to facilitate transitions from nursing homes and institutional settings to community based residences.
- **Community First Choice** The Executive Directors of The Arc of Colorado and The Arc of Arapahoe and Douglas serve on the CFC Council providing input to CHCPF for possible implementation of a provision of the Affordable Care Act which would increase the share of federal support for Medicaid long term services and supports. Community First Choice is intended to encourage states to make benefits such as personal care, home-maker services, health maintenance, and other supports available in the community to avoid costly nursing home or institutional placement.
- Behavioral supports and other treatments for people with Autism—The Executive Director of The Arc of Arapahoe and Douglas counties has long been a leading advocate for coverage of autism treatment for CO children. In 2014, she and the Executive Director of The Arc of Colorado with support from other advocacy organizations and Senator Irene Aguilar, secured a meeting with HCPF officials to address the issue of coverage for autism treatments either through the Medicaid state plan or Medicaid EPSDT (Early Periodic Screening, Diagnoses, and Treatment). The 2015 budget presented by Governor Hickenlooper requests major improvements in the Children with Autism waiver by eliminating the cap on the number of children to be covered and raising the age limit as well as the amount of services provided. The Arc supports this recommendation and will continue to advocate for EPSDT coverage as well as coverage for treatments for adults with autism.

#### **Representation of The Arc**

The Arc of Colorado is represented through service on:

- Community Living Advisory Group
- DD Waiver Re-design
- Regional Center Task Force
- Community First Choice Council
- Colorado Choice Transition Advisory Council
- JFK Advisory Council
- CANDO-and Medical Mental Health Subcommittee
- Adults without Dependent Children Medicaid Expansion Advisory Task Force
- Long Term Services and Supports Assessment task force
- Rocky Mountain Human Services Mill Levy Advisory Committee
- Colorado Non Profit Association Public Policy Committee
- Mental Health Center of Denver–Mental Health Crisis Intervention and Stabilization Advisory Group

## Public Awareness/Community Outreach

#### Film Festival

The Arc of Colorado with all local chapters of The Arc celebrated national Developmental Disabilities Awareness Month in March with the 3<sup>rd</sup> annual *Achieve with Us* Colorado Film Festival. Showings were held in Colorado Springs, at the Candlelight dinner theater in Johnstown, and Denver. About 850 people attended one or more showings.

In 2014, we produced a film--*For Fathers*—about the issues and challenges faced by fathers of children with IDD.

Sponsors: Colorado Chapters of The Arc, Alliance, arc Thrift, , Rocky Mountain Human Services, Colorado Springs Gazette, Colorado Springs Independent, Developmental Pathways, 1st Bank, JFK Partners, PASCO, The Legal Center for People with Disabilities and Older Adults, The Resource Exchange, Jewish Family Services and the Stargazers Theatre and Event Center, DPC Development company.

Community partners: The Autism Society of Colorado, Colorado Cross Disability Coalition, Colorado Developmental Disability Council, Candlelight Dinner Playhouse, Colorado Fund for People with Developmental Disabilities, Colorado Gerontology Society, Colorado Respite Coalition, Colorado Special Education Advisory Committee, Denver Children's Advocacy Center, Denver Film Society, Denver Film Center, Easter Seals of Colorado, El Grupo VIDA, Ecographics, FASD Council, Hooligan Productions, Parent to Parent, Peak Parent Center, People First of Denver, Phamaly Theater Company, Rocky Mountain Down Syndrome Association, Timberline Church Network, Troy's custom Tee's, Tri-County Health Department, and People First of Larimer County.

Plans are underway for the 2015 series.

#### **Families in Action**

The Arc of Colorado with the Association for Community Living in Boulder County, The Arc of Larimer County and The Arc of Weld County successfully launched Families in Action as an annual event to bring together families of young children with IDD for networking, education and an introduction to the life-long value of engagement with The Arc. For two and a half days in June, parents, grandparents, and children from 27 families gathered with staff and volunteers from chapters of The Arc for a jam packed "retreat" at the Estes Park YMCA camp. All told, more than 165 people in bright green Families in Action T shirts learned and played together in the Rocky Mountains.

Chapters of The Arc and other sponsors, including arcThrift, covered all the costs of the event so that families could participate. Break- out sessions covered topics ranging from "Why Language Matters" to "Accepting the Hand You've Been Dealt." The days and evenings were filled with activities for adults and for all the children who attended. Since that June weekend, strong family networks in all three communities have continued to flourish and build relationships with local chapters of The Arc.

The second annual FIA event is planned for June, 2015.

#### PLAY

In 2014, the Professional Baseball Athletic Trainers Society (PBATS) and The Arc launched a partnership to promote the inclusion of people with disabilities in sporting activities nationwide.

The Arc of Colorado, with local chapters, participated in the PLAY (Promoting a Lifetime of Activity for Youth) campaign with the Colorado Rockies at Coors Field. In July, 12 kids from Douglas County to Grand Junction joined Rockies players for a morning of physical and nutrition education and the opportunity to see the Rockies play later that weekend. PLAY participants were "over the moon" from their experience with the team.

#### **People First**

Heidi Haines, Project Specialist for The Arc of Colorado also serves as the advisor for the Denver area People First Chapter. The chapter meets regularly at The Arc of Colorado—Logan Towers Conference room. The Board meets at Advocacy Denver. Heidi routinely assists the Denver group in board as well as membership meetings and provides support for the chapter when they engage in statewide events with other self-advocacy groups. In August, 2014, Heidi accompanied the Denver chapter to the statewide meeting of advocates and advisors in Alamosa and also attended the national SABE (Self Advocates Becoming Empowered) convention in Oklahoma City in October.

Vicki Wray, member of the board of directors of The Arc of Colorado, was elected as a Regional Representative for the SABE Board at the October convention.

#### Other community outreach activities:

In 2014, The Arc of Colorado has participated in, exhibited at, or provided sponsorship for:

- Colorado Respite Coalition
- Alliance Leadership Summit
- Autism Awareness Day at the Capitol
- Colorado Special Education Advisory Committee Resource Fair
- Colorado Cross Disability Coalition Awards Luncheon and Leadership Summit
- Parent 2 Parent Mothers' Day Tea
- Rocky Mountain Human Services annual event
- 2014 Coleman Institute Conference
- CO Non-Profit Association Fall Conference and Spring recognition luncheon
- Developmental Pathways 40<sup>th</sup> anniversary gala
- Colorado Respite Coalition
- Mosaic Services "Meet the Team"
- CO Guardianship Alliance presentation
- CO Fund for People With Disabilities Anniversary event
- Foothills-Gateway Person Centered Training team
- Arc Thrift Annual Gala
- Brain Injury Alliance annual breakfast and legislative event

- Community Options Annual Meeting
- Alliance Annual Day at the Capitol
- Colorado Fiscal Institute Budget 101
- Starpoint Anniversary Gala
- Families at the Forefront of Technology

#### Local Chapter Support

Staff and/or Board members of The Arc of Colorado attended annual meetings for

- ACL of Boulder County
- The Arc of Weld County
- The Arc of Larimer County
- The Arc–Jefferson, Clear Creek & Gilpin
- Advocacy Denver

We participated in and/or provided support for numerous other local chapter activities including:

- The Arc–Jefferson, Clear Creek & Gilpin Summit of Hope
- The Arc of Pueblo Golden Tortilla Fundraiser
- The Arc of Aurora Summerfest
- The Arc-Jefferson, Clear Creek & Gilpin Annual Picnic
- The Arc-Arapahoe and Douglas Annual Picnic
- The Arc of the Pikes Peak Region Valentine's Day Dance
- The Arc of the Pikes Peak Region Annual Awards Dinner
- The Arc of the Pikes Peak Region/The Resource Exchange Town Hall

# Expanding the Arc to Areas of Colorado not Served by a Local Chapter

The Board of Directors of The Arc of Colorado supported initiatives to fund (\$30,000) start up efforts for establishing a local chapter of The Arc in southwest Colorado. In 2015, we hope to see a new chapter up and running in the Durango area. The Arc of Mesa County will provide leadership to the parent group working on forming the new chapter.

The Arc of Colorado also supports The Arc of Mesa County for individual advocacy efforts in areas of the Western slope outside of Mesa County.

Also in 2014, The Board of Directors of The Arc of Colorado agreed to assist (\$30,000) The Arc of Weld County to expand advocacy and parent education to some of the under-served eastern counties.

Lastly, The Arc of Colorado provides advocacy to people who have family members with an I/DD in areas not served by a local chapter. In 2014, staff assisted approximately 25 families from Kiowa to Summit County.

#### Governance

**Board of Directors:** The Board of Directors of The Arc of Colorado, for the first time in over 10 years, has representation from all 11 local chapters of The Arc. Additionally, through the hard work of the Nominating Committee, all six at-large seats are filled and include a Board member who lives in an area of the state not served by a local chapter. With 20 members on the governing board, The Arc of CO has a wealth of talent and interests at hand to guide our work in the coming year.

**Committee structure:** The Arc of Colorado by-changes proposed for approval at the 2014 annual meeting establish three standing committees: Personnel, Governance and Finance. The public policy committee would be eliminated as the entire membership, through chapter representation, is actually represented in policy related effort. The President appointed an ad hoc Governance Committee in 2014 which will convert to a standing committee when the by-laws are modified. The first task of the committee was to recommend the by-law changes that were originally contemplated in 2013.

The Governance committee also has plans to provide board training and will work with the Personnel committee to ensure that The Arc of Colorado operational policies and procedures are consistent with our mission.

The Personnel committee will present personnel policies to the Board of Directors for adoption in January, 2015. We are grateful to ACL of Boulder for sharing that chapter's newly developed personnel handbook which has served as a guide for The Arc of Colorado.

Over the past decade, the Executive Committee of The Arc of Colorado has also functioned as the Finance Committee largely because other Board members did not have the time to serve on a separate Finance Committee. In 2014, we were fortunate to have several members of the Board express interest in this topic and the Treasurer convened a committee to review The Arc of Colorado investment portfolio and make recommendations about investment strategies as well as propose policies for utilization of chapter resources. The Executive Committee continued the practice of working with the Executive Director on budget development and financial reporting. In 2015, the Finance Committee, chaired by the Treasurer, will refine budget development and financial reporting procedures.

### Financial resource development

Across the country, state chapters of The Arc have struggled with securing sufficient financial resources to carry out the primary mission of public policy advocacy. State chapter structures vary from state to state but most derive resources through a combination of local chapter affiliation fees or dues, fund-raising and revenue producing projects such as management of pooled trusts. Fund-raising for state chapters requires a careful balancing act to ensure that the state organization does not compete with local chapters for the same resources.

The annual allocation to The Arc of Colorado from the arcThrift Allocation Committee was significantly increased in 2013 and a nice increase was received again in 2014. That allocation, in addition to savings realized by staff reductions and resource management as well as an increase in individual donations, has allowed The Arc of Colorado to function and increase outreach without dipping too deeply into reserve funds. The investment portfolio has been well managed and in 2014 will produce about \$10,000 in interest and dividends.

Through participation in CO Gives over the past three years, The Arc of Colorado has enjoyed a modest uptick in individual donations. The chapter now has online donation options through the website.

The by-law changes proposed at this meeting will clarify what has been a standing practice of ensuring that the state chapter does not actively pursue fundraising in areas of the state served by a local chapter without the express permission of the chapter.

In 2014, The Arc of Colorado Executive Committee with the Executive Director worked hard to clear up mistakes that had been made over the past two years in federal tax reporting and payment. We engaged an accounting firm to manage bookkeeping as well as state and local tax payments and financial reporting. The accounting firm did a thorough retrospective review of 2011, '12, and '13 payroll, 401 (k) plans, and other liabilities to ensure that all obligations were up-to-date. We are confident that the organization is on sound financial footing and has good reporting processes in place.

# The Arc US

Colorado presence at the national level of our organization has increased significantly over the past several years and our influence continues to expand.

Nine representatives from Colorado attended the annual Disability Policy Seminar in Washington in April of 2014. We were able to visit all seven offices of Colorado House members and met with both Senators.

Colorado chapters of The Arc were well represented at the 2014 national convention. Thirty seven staff, board members and other volunteers from 10 local chapters and The Arc of Colorado participated in three days of inspirational, educational, and organizational business activities in New Orleans. Convention participation from Colorado has quadrupled in the past seven years.

In late 2013, The Arc US President, Nancy Webster, visited Colorado as a featured speaker at The Arc—Jefferson, Clear Creek & Gilpin Counties annual meeting; The Arc of CO also hosted a reception for Nancy during that visit. In 2014, Nancy and Chief Executive Officer, Peter Berns, came to Colorado for the Denver session of the DD Film Festival. During that visit, we arranged a tour of the Linda Crnic/Sie Foundation Down Syndrome clinic and research lab at the University of Colorado Anschutz campus. Nancy and Peter also attended a reception hosted by Jeannette Weller to introduce them to Colorado supporters of The Arc. Additionally, in 2014, Ron Brown, then Vice President and now the newly elected President of The Arc, visited Colorado to attend the annual awards dinner for The Arc of the Pikes Peak Region. Ron has indicated that he plans to visit Colorado again during his term as President.

The Arc of the Pikes Peak Region was selected as one of five chapters of The Arc to pilot implementation of The Arc's <u>National Center on Criminal Justice and Disability's (NCCJD)</u> "Pathways to Justice" Training Program. Through this program, chapters will help build the capacity of the criminal justice system to effectively identify, serve and protect people with intellectual and developmental disabilities (I/DD), many of whom have "mild" disabilities that often go unnoticed among criminal justice professionals without appropriate training.

Lori Ropa, ED of The Arc—Jefferson, Clear Creek & Gilpin Counties and Wilfred Romero, ED of The Arc of the Pikes Peak Region were elected to serve on the Steering Committee of the National

Council of Executives of The Arc and Marijo Rymer was appointed this week as co-chair of the NCE Board Governance committee.

Randy Patrick was re-elected to The Arc Board of Directors by the delegates to the 2014 national convention and will serve his third term on the Board.

The Arc is the nation's oldest, largest, and most effective organization advocating for people with intellectual and developmental disabilities and we can all be proud of Colorado's presence at the national level.

Respectfully submitted

Randy Patrick, President Marijo Rymer, Executive Director

Heidi Haines, Project Specialist